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How we express blood disorders such as Thalassemia to Children versus adults.

Thalassemia is a blood disease in which people are not able to produce enough hemoglobin in their blood. Hemoglobin cells transfer oxygen to the rest of the body. These cells are made in the bone marrow of the body. People who suffer from Thalassemia will often complain of tiredness or fatigue due to not having enough oxygen in the blood. Those who suffer from Thalassemia will often have a darker color in blood due to hemoglobin levels being lower than the average human. Anemia is also a common disorder associated with Thalassemia because Anemia can sometimes *cause* Thalassemia. Anemia is the condition at which you are not able to produce enough iron in the blood.

Those who are Anemic also run the risk of being Thalassemic. Both of these disorders are hereditary which means that they run in the family. Either the mother or the father will have this blood disorder and pass it to the child. When you have this disorder you cannot get rid of it and you have this disorder for life. However, this is not a terminal disorder which means you will not die from it, but you may die from complications with the disorder. Those who have complications often have a severe form of this disease since there are two forms. The two forms are Alpha Thalassemia and Beta Thalassemia (or ass written by a doctor α Thalassemia and β Thalassemia). Alpha Thalassemia is the more harmful of the two of these and can cause cancer. Beta Thalassemia is the non severe type of Thalassemia. Treating both of these disorders in the severe form would mean blood transfusions or taking iron pills to increase the levels of oxygen and iron to the blood to keep it at a healthy level. Some people who suffer this disorder will be recommended not to take iron pills due to having a healthy enough level iron in the blood, but being low in hemoglobin levels. Treating the disorders with any of these methods runs with a risk of having future medical problems such as AIDS, cancer or even complications with pregnancy.

What I hope to find out it how we can avoid spreading this blood disorder and how we can treat this blood disorder. I also want to know how many people suffer from this and how we can explain this blood disorder in a way that makes sense to everyone who suffers from it. I hope that I will be able to explain this to someone in my family or even my future children. I want to be able to tell them in a way that makes sense to them and that will not hurt or harm their feelings.

Literature Review: Being a doctor is not an easy job, especially when you are a family doctor. The daily problems of learning how to speak to your patient who may have learning disabilities, hearing problems, or even just being able to speak to them at the level to which they will be able to understand what you are saying to them are just a few hurdles that a doctor will have to learn to overcome. In the article titled “Listen Up Doctors: Here’s How You Talk to Your Patients” by Mary Elizabeth Williams, she explains that doctors have some common issues that *she* believes need to be solved. She speaks on three issues she believes that the doctors need to focus on. In her first section titled “Take your hand off the goddamn door already”, she explains that the doctor has us waiting longer than they assess the patient. She also quotes a doctor who explained that when the doctor comes into the room to speak with us and looks us in the eye, it makes us feel like we have been meeting with them a while when in all reality the time that we have waited has been longer than the actual meeting time. (Bylund, Williams “Listen Up Doctors: Here’s How You Talk to Your Patients”). Williams also explains that the doctor should at least act like they are willing to spend time and talk to the patient rather than throw information at us as they are walking out of the door. When a doctor does this, it creates a sense of lesser importance to the other patients that are waiting in line. This is because body language has a lot to play into how patients perceive their importance to their doctor and how their level of comfort is with their doctor. She also explained in her second section titled “Remember that this random collection of faulty parts is a person”, that doctors tend to look at patients as a diseased person and not a person with a disease and that most doctors tend to lack an understanding that the patient comes *before* the disorder and not the other way around. In her eyes the doctor that she visited seemed to care more about how she was treating the disease and not so much about how she felt about her disease.

In her third section titled “Consider that the patient is telling you something charts don’t”, she explains that we as patients should not expect the doctor to know everything, but she also says that it is our responsibility to tell the doctor the whole truth and nothing other than that. It is also the doctors job to do everything that they can possibly do instead of telling them something that they want to hear and not what they need to hear. As far as communicating to the patient, she expresses that doctors should understand that we may not have the same level of education and therefore, are not able to fully understand the things that are going on in our bodies to the extent that they know it to be. Doctors have to be able to connect to their patients on a level that they understand and not what they as doctors understand. She feels that the doctors should take a step back when trying to tell us everything under the sun about the needed procedures that we have to get done or even just as simple as the details about how to manage a healthy body weight. In her words, they tend to just throw words or phrases at us that make little to no sense at all. If we do not understand how treatment works, then how are we going to be able to treat ourselves or understand our treatment process? It takes someone with good patience and a great sense of vocabulary to tell someone how they can get better and how they can apply what they’ve learned from their doctors into their own lives.

Another woman by the name of Nancy Ainsworth-Vaughn wrote a book titled Claiming Power in Doctor-Patient Talk she explains that doctors and patients should have equal power to speak to one another and they should respect what one another has to say. This would mean that the doctor would have to be respectful of the patients’ circumstances both financially and also physically as well as the patient being understanding that the doctor knows how to treat their symptoms to the best of his or her ability. She explains that in most of the studies that she has seen from different countries show that the patients often have to answer questions that a doctor is asking them and therefore is giving the patient little to no room to speak especially if it is a yes or no question. During her research that she has done, she noticed that most of the people she’s dealt with do not have the basic question answer system, but instead she says that “Instead I found a wide range of speech activities and overall patterns of talking and listening (Ainsworth-Vaughn Claiming Power in Doctor-Patient Talk ). She also has found out that the patients feel more comfortable telling the doctors information as well as being able to share the power with the doctor and that the doctor was willing to share the power with them (Ainsworth-Vaughn). According to Cathy Charles, Amiram Gafni and Tim Whelan the authors of Shared Decision –Making in The Medical Encounter: What Does it Mean? (or it takes at least two to tango), believe that there are different models for how physicians or doctors make decisions for their patients. One of the ways that they do this is a parental style, meaning that the physician and or doctor *makes* the choice *for* the patient while trying to see what is the best method for the patients’ treatment (Whelan). This role that the physician is playing only happens when the patient just seems to go along with what the doctor says instead of standing up for what they want for treatment. They tend to see the physician as the one who knows what is best and they should just not put a up a fight for what they want. The problem with this is when the physicians only pick and chose what they say, meaning that they give the half truth about what the treatment will really be like. In emergency situations doctors or physicians must make choices that they feel could save the persons’ life. When this do this it makes them face the challenge of ethics.

In the essay titled “Laws that conflict with the Ethics of Medicine: *What Should Doctors Do?* By Dena S. Davis and Eric Kodish, states that everyone has to deal with certain moral obligations that might interfere with the law (Kodish). Doctors are held to a higher standard because they must follow a code of ethics on top of their own personal beliefs of how to help a patient. Some doctors are forced to break the rules for some patients more than others. However, they are expected to tell the whole truth and they cannot spread false information because that could cause damage to the patient and in turn cause more hurt and or harm. Doctors are often faced with three major problems: “… doing the best they can for their patients, following the law, and protecting themselves, from the consequences of breaking the law (losing their licenses for example)” (Kodish). The boundary lines have been made for the doctors and they must make a choice as to how they associate with their patients. They either follow ethics or they follow what they believe is best. Doctors are asked to take care of people who may be carrying diseases that could harm or kill them. They really must make a choice to either have the patient suffer as they walk away with a clean bill of health, or risk their lives trying to save a life. At the same time, the doctor must be willing to understand their patients wishes. The most interesting thing about all of this, is that if a patient is an illegal immigrant is that the doctors are not allowed to call the police because they will “…betraying not only the patient but their own professional commitments as well” (Kodish). This is important to understand because doctors have laws and or codes they must abide by, but sometimes the laws have to be broken in order to do what is best for the patient. In cases with children, parents may be asked to explain what the medical issue is to a child.

A mother by the username of Zahra asked the fellow mothers on a website titled “Thalassemia Patients and Friends” to help her figure out how to talk to her son who is 6 years old about Thalassemia. Another user by the name of Sharmin responded saying that Zahra should start talking to her son about the small things and that she should tell him these things at a level that he can understand them and that he can handle them. She also warned her that she should not overwhelm the child with information, but instead try her best to tell him the details he should know for a six-year-old boy (Sharmin). She was sure to tell her that she could turn a negative experience into a positive one and to make sure to tell him that even though he might be feeling down and out about his disorder, he should never feel alone and that he should always find something positive about himself. It is not easy to raise a child with Thalassemia whether they are related to you by blood or you have adopted them.

Amy Long is a mother to a child who suffered from Thalassemia. She decided to share her story through a website titled [www.thalassemia.org](http://www.thalassemia.org), where the article title is “Parent Perspective: Raising a Child with Thalassemia”. She explains that her daughter was diagnosed with this disease when she was eight months old. The family had taken her to a hospital only for them to be told that she had physiological anemia which is when a child experiences all of the physical symptoms of the disease such as pale face and very low amounts of hemoglobin. Her mother was told to include certain foods in her diet, but after two months of trying the foods did not help her. Her mother was forced to take her to a hospital where she could get help as to figure out what was the real problem. They took her to a Children’s hospital in Chongqing, China only to find out that she had Thalassemia and was in need of blood transfusions. Her family had never heard of this disease before and they didn’t know what to do so they had to wait while her blood was being transfused. Luola’s mother tried every treatment option that was possible for her to have and they never gave up hope. They then decided to try to move the the United States in order to help broaden the treatment options. Once the family moved to the United States they found Cooley’s Anemia Foundation which helps not only patients with Anemia, but also with Thalassemia. Cooley’s foundation helped Luola’s parents to understand the disease and to overcome their fears that they have for their daughter. They had to overcome the challenge of learning English before they could properly be able to understand what was going on with their child. What Luola’s mother wants everyone to know is that having this disease will not limit you and how you experience life, and that you can also gain an understanding of the disease and “…gain knowledge but also gain confidence-the confidences to be a strong person both mentally and physically” (Long).

Primary Research Methods and Findings: What I wanted to know from all of this is how do we communicate diseases or disorders to one another. How I went about finding this information was interviewing two women. I chose to do an interview with a doctor and my mother because I wanted to see how the explanations varied between the two of them. According to a doctor who was kind enough to allow me to interview her, she explained that “We speak to all of our patients at a third grade level, but most of this depends on the level of education of the patient or patients that we treat” (Holmon). As a doctor she does not directly work with children in her practice, but was able to explain to me that in order to describe a disorder to a person of any age we have to get on their level (Holmon). As a doctor they must be able to handle the challenges associated with understanding that sometimes the patients will not want to seek help from a specialist who will be able to describe the disorder to them in a better “light” to them. When I interviewed my mother, she explained the disorder (Thalassemia), in a way that she understood. She described this disorder as follows: “Thalassemia is a condition that causes low hemoglobin levels” (King). When both of them had been asked about how they would talk to an adult about the disorder the doctor would speak to the adult at their education level and talk about how they can manage their symptoms and how they can manage them. My mother on the other hand, would describe it as something that everyone in the family has and that we are all dealing with it together. Both of these women had different methods of handling how to speak to an adult. When we began to talk about treatment methods my mother only was aware that blood transfusions as well as iron pills were the main two options for people who are living with Thalassemia. However, the doctor was able to give me more insight as to how this disorder occurs.

She began to tell me that it was hereditary (which I had known already), but what I didn’t know was that it was a recessive trait that comes from both of your parents. She was able to tell me that if I did not want my child to have thalassemia that I would need to see a genetic counselor before I was to have children. She told me that I would need to have the person that I wish to marry be tested for thalassemia (both the trait and the disease). The doctor also explained to me that I could take Folic pills to increase my iron levels and my hemoglobin levels. Surprisingly, I cannot become a vegetarian because I need to continue eating red meat. Most people would think that because you are consuming less meat and more vegetables that it is going to help you, but instead in my case, it will make things worse. She recommended that I keep taking vitamins and that I need to include more fruits and vegetables in my diet. When I combine with what I found out from both of these women with what I see online, I see that this blood disease effects one in four people in the United States and that we have ways of preventing the spread of it, but these methods cannot be fully effective. According to [www.thalassemia.ca](http://www.thalassemia.ca) “One in four pregnancies result in a child having normal blood, two in four will have thalassemia minor and that one in four will have thalassemia major” (thalassemia.ca). This information can be found in figure one. The only other way we can make this disease known is to talk to everyone we know about it and go to regions where this is prevalent from and get the people from these areas tested.

Figure One

Discussion: In my research, I was able to find out a lot about how I can deal with this blood disorder. What I wanted to find out from this was if my mother was able to explain the disease in the way that a doctor would be able to and I came up with a yes and no situation. The doctor who was kind enough to allow me to interview her gave me the run down about how she would talk about the disease to an everyday patient and my mom told me what she knew about the disease. What I knew coming into this was that the disease is not contagious like the common cold or the Flu virus, but it was a blood disease meaning that you can only contract it through blood. In my personal experience with a person telling me what the disorder was, I cried. I had little to no idea how to deal with having the blood disorder. I was diagnosed in the Spring of 2015 with Anemia and Beta Thalassemia. My doctor did not directly call me, but instead it was the nurse who works with my doctor. She kindly explained to me that I would not die from this blood disease, but I would need to get my blood drawn on a regular basis in order to make sure that the levels of iron and hemoglobin I have are not at a dangerous level. What I found to be interesting was the fact that the woman on the phone could hear in my voice that I was crying and upset because I didn’t know what it was. Most people who are nurses would not take time out of their day to calm a patient down to make sure that they were okay, but this woman did. She explained to me that this disease can not harm me unless I make drastic lifestyle changes such as drinking and smoking. When I had saw my doctor during my spring break I had told her everything that I was going through. I told her that I was taking vitamins, I was drinking water on a regular basis and I also told her that I had been feeling cold and that issues with menstruation had occurred. She began by giving me the regular physical and then started assessing me and looking at my skin since most Anemic people have a jaundice or yellow pale look in their skin. She looked at my hands and my nails to see if they had curved under which is another sign of Anemia. She asked me if I had been eating ice and I was honest with her.

She told me to sit up when she finished the exam. She looked at both my mother and I and said that she wanted to get a blood test run and that the hematology lab was open and I was to go immediately. My doctor was kind enough to spend some moments explaining to me that she wanted to make sure that I wasn’t diabetic. Unlike most doctors she pushes her patients to be honest with them so that she can help us to be on a healthier path. She switched her attention from me to my mother and asked her if she had been managing her blood sugar because she is a diabetic. Of course my mom lied and the doctor knew it and told me to hold my mom accountable to taking her blood sugar on a daily basis.

When the doctor left she shook my hand and said that everything was going to be okay and that I would need to come back to check up with her to make sure it is under control. We left the doctors and went to the hematology lab. I didn’t sit in the waiting room for too long because the people who drew blood work very fast. When I sat down I saw a young girl and her mother in the waiting room. When they called the little girl into the room, she seemed like she was ready to cry. At first I wasn’t afraid, but when I saw her begin to cry I began to have anxiety overwhelm me. Which I didn’t know was also a symptom of Thalassemia. Once I was called into the room to get my blood drawn, I had warned the nurse that this was my first time and that I was scared and wanted it to get over with. I also warned her that my veins were deep. My mother sat in the corner chair holding my hands as the nurse counted to three and stuck the butterfly needle into my arm. My immediate response was to suck in air which scared her, she then told me to breath. My face went from brown to pale grey in a matter of seconds. I saw the vials that she needed to fill up and it was three of them all with a different amino acid. She talked to me to calm me down and before I knew it each vial was filled.

My experience with my doctor has been great. I can say that we have an open line of communication and she has never been in a rush to talk to her patients and then leave to talk to the next one. What I found out for myself is that out of all the doctors I could have, I’ve landed with one who keeps track of all of her patients and knows out personalities. Learning about Thalassemia has helped me to grow as a person and has helped me to personally know how to handle this disease. As a person who has seen many doctors, I would recommend people to see their doctor yearly even if they hate it. It never hurts to educate yourself about a problem that you have been facing. The only damage you are doing by not seeing them is telling yourself that you will be okay and that the doctor will only make things worse. I had to beg my mother for months to take me to a doctor before I found out that I had this blood disease. Since I have been going to the doctor for regular check ups, I have felt a sense of relief. I urge people to have an open honest friendship with their doctor. They are there to help you not hurt you, and if they add medication it is to help a problem and not make it worse. I also recommend following the doctors’ orders because if you don’t it will land you in one of two places, having to see the doctor more often or ending up on more medication.

I know this because my own grandmother HATES seeing the doctor. She is now forced to go 3-4 times a year because she has a *long* list of medical problems. She could have avoided having to take the medication that she is on if she had just gone to see the doctor. Every time I see her I urge her to go to the doctor because the doctor she sees gives her not only good advice for her health, but personal advice. I strongly believe in seeing a doctor because I believe so deeply in doctor-patient relationships. I have always been honest with my doctor so that I do not end up like my grandmother. Having a doctor who can speak to you in a way that makes sense to you makes everything a little better. Especially if you are dealing with a disease that can kill you; understanding the causes and how you can treat and potentially overcome your disease is important. In my opinion communication with your doctor is everything. So in other words, do not let a health problem become worse *before* you have to see a doctor, get yourself checked out immediately. I also strongly believe that the patient should never leave the doctors office without any sort of answers, but instead they should take the time and come back multiple times until the problem has been solved. I understand that some problems are not as easy to solve and that others take longer to solve, but if the patient works with the doctor, the chances of being on a road to recovery are much higher. The doctor whom I interviewed has a personal relationship with me. This woman started out as nurse and was part of the c-section that took place for my birth. When I interviewed her, she asked me at the end if I was taking care of myself and not my disease. She gave me advice on how to manage it and that if I needed anything that I should call her. She also knows the doctor that I see on a regular basis, so skipping a doctors appointment is not something she would recommend to me or anyone else. My mother has also helped me to understand some of the things that she went through with the disease and what I need to look out for in my own personal health. This not only has helped me to see that the disease is not only manageable, but any health problem that I may or may not have in the future, is also manageable as well.

That cold feeling in the tips of your hands and in your feet could mean one of two things. Either you are anemic or you have poor circulation. As a person who suffers from this disease I urge everyone to educate themselves about a disorder they have. To finally know the source of the problem is a freeing situation. For some like me, the battle has only begun. Knowing what you are going through can make you a better person. I want to see more and more people speak up about disease and disorders that they face and be bold about it. I told my roommates about my blood disease and what they need to do incase I need to seek medical help. I took the time to educate them and tell them what it was and how I am treating mine. The most important thing that I have learned from myself through reading this information is that I am a strong person and that I know I can handle this. I have had this disease all my life and I know understand enough to tell my future children about his disease if they ever are diagnosed with it.

Works Cited Page

Appencies

The topic that I would like to explore would be Thalassemia and how a doctor would explain the blood disorder to an adult verses a child. What I would need to do is see some of the medical terminology for the words associated with the disorder. The reason that I want to do this topic is because I have this blood disorder and want to know more about it. It would take a lot of sources to find causes of this disease and also how the variation of explaining the word(s) to the average joe vs another doctor would differ.

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